

THE FEASIBILITY OF ONLINE VIDEO CALLING TO ENGAGE PATIENTS WITH CYSTIC FIBROSIS IN EXERCISE TRAINING

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RUNNING TITLE: Using Skype to deliver exercise in cystic fibrosis

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

ABSTRACT

Introduction: Physical activity (PA), including structured exercise is an essential component in the management of cystic fibrosis (CF). The use of telehealth such as video-calling may be a useful method for the delivery of exercise and PA interventions, though the feasibility of this remains unknown.

Methods: Nine patients with CF (three female, six male, 30.9 ± 8.7 years) volunteered to participate. Participants completed an 8-week exercise training intervention conducted via Skype, using personalised exercises, with all sessions supervised by an exercise therapist. Feasibility was assessed by demand, implementation, practicality and acceptability. Changes in anthropometric, pulmonary, PA and quality of life (QoL) variables were also assessed.

Results: Two male participants withdrew from the study, citing lack of available time. Remaining participants found use of Skype useful, with a mean satisfaction rating of 9/10, and three participants requesting to continue the sessions beyond the duration of the study. Mean compliance with sessions was 68%, with mean duration of sessions being 20 minutes. A total of 25% of calls suffered from technical issues such as video or audio lags. Anthropometric, pulmonary, PA and QoL variables remained unchanged over the course of the study period.

Discussion: The use of Skype to deliver an exercise intervention to patients with CF was found to be technologically feasible, and acceptable among participants. Findings have implications for clinical practice and could allow care teams to engage patients remotely in exercise. Further research is required to assess the efficacy of this modality on increasing PA and associated health outcomes.

KEYWORDS: exercise, Skype, intervention, personalised training, telehealth, acceptability

1. INTRODUCTION

It is well established that physical activity (PA) – which includes structured exercise – is beneficial for patients with cystic fibrosis (CF), with increased PA being associated with higher levels of aerobic fitness (1) and slower rates of decline in lung function (2). Patients are therefore recommended to remain physically active and exercise frequently, with global PA guidelines of 150 minutes of moderate-vigorous PA (MVPA) per week for adults, and 60 minutes of MVPA daily for children also being appropriate for patients with CF (3). However, adherence rates to treatment (including exercise) are variable (4) and it has subsequently been suggested that supervision of exercise, and its subsequent incorporation into the home environment, could improve adherence (5).

Telehealth technologies, including video-calling software such as Skype, self-care and monitoring applications can potentially change how patients with CF engage with healthcare services and reduce burden of care (6), improve monitoring (7) and potentially reduce costs associated with healthcare delivery (8). Furthermore, factors that may negatively affect health outcomes, such as risk of cross-infection (9) could potentially be overcome by the use of telehealth systems.

Previous research suggests that patients with CF are willing to adopt and utilise such telehealth technology (10), and that use of an online platform to engage patients in PA is feasible and acceptable (11). Furthermore it is feasible for both patients and practitioners to assess exercise capacity remotely (12). Whilst this data provides evidence for the feasibility of remote monitoring of PA and exercise capacity, the feasibility of delivering a supervised exercise intervention is yet to be explored.

Supervised exercise training is effective in improving lung function and exercise capacity in patients with CF (13). However, the gym- and hospital-based nature of these interventions can burden patients with increased travel and parking costs, gym membership fees and exposure to cross-infection risks through regular hospital visits. Home-based interventions may also positively affect lung function in patients with CF (14) and therefore warrant further investigation and implementation.

It is currently unclear whether implementing supervised, online, exercise sessions using telehealth is feasible or acceptable among patients with CF. Therefore, this study sought to assess the feasibility of utilising an online video-calling platform to engage patients with CF in a personalised exercise regimen. This was primarily assessed by demand, implementation, practicality and acceptability of the intervention; and secondly by identifying issues associated with the online delivery of the intervention.

2. METHODS

2.1. Study Population

Nine patients (three females, six males; 30.9 ± 8.7 years, range = 15.5 – 42.1) with CF were recruited from outpatient clinics at the Royal Devon and Exeter NHS Foundation Trust Hospital. Participants were eligible to participate if they were ≥ 14 years of age and clinically stable at the time of recruitment. To minimise impact upon usual clinical service, recruitment was staggered over seven months (March – October 2017). Participant characteristics are listed in Table 1.

2.2. Ethics Approval

All participants provided written informed consent (or assent, with parental consent where

applicable) upon enrolment. Ethics approval for this study was provided by an NHS Regional Ethics Committee (Cornwall & Plymouth REC) and the Health Research Authority (16/SW/0175).

2.3. Timeline

The period of investigation lasted 12-weeks, with a video-calling intervention occupying the first 8-weeks, and a further 4-week observation period. Figure 1 details when measurements associated with the study were taken, and when the intervention period occurred.

2.4. Intervention

All participants undertook 8-weeks of video-calls (Skype™, Microsoft, Luxembourg), supervised by the same exercise therapist, receiving up to 3 supervised exercise sessions per week.

Skype was chosen as it was freely available for all participants and provided secure end-to-end encryption (therefore falling in line with hospital requirements for computer software). All exercise sessions were booked as per any regular outpatient appointment, being pre-arranged between participant and therapist at convenient times for both parties, provided these were a) within working hours for the therapist (0800 – 1700) for security and safety reasons, and b) the gymnasium facility was available. All sessions were placed upon the hospital ‘Patient Administration System [PAS]’ as per usual clinical appointments. For the exercise therapist, sessions were delivered on a laptop connected to the hospital Wi-Fi network, in a small gymnasium on an outpatient therapy ward that could be booked by any staff member within the ‘Therapy Services’ division of the hospital trust.

Exercise sessions were intended to be 30 minutes in duration, as per national PA guidelines (3). All sessions were undertaken in participants own home, on a one-to-one basis with the exercise therapist. Content of each session was personalised to each participant for the purposes of this study, dependent on equipment available in participants homes. Some participants utilised equipment such as bikes and treadmills, with others using free-weights, resistance-bands or body-weight exercises. The frequency, intensity and timings of exercises throughout the sessions were aligned with participants own preferences and capabilities, although a broad ‘interval’ approach to exercises was adopted as this has shown to be beneficial to individual with CF (15), and provides regular breaks for individuals to recover.

2.5. Anthropometric and Pulmonary Measures

Stature was measured to the nearest 0.1 cm (Holtain stadiometer, Crymych, UK) and body mass to the nearest 0.1 kg (Seca, Birmingham, UK), with body-mass index (BMI) subsequently calculated. Body-fat percentage (and subsequent fat-free mass) was identified using bio-electrical impedance (Quadscan 4000; Bodystat, Douglas, Isle of Man). Estimates of arterial blood oxygenation (SaO₂) were recorded using a pulse-oximeter (Nellcor; Medtronic, Minneapolis, USA). Measures of forced expiratory volume in one-second (FEV₁), forced vital capacity (FVC) were obtained using a spirometer (Vitalograph Alpha; Vitalograph, Buckingham, UK and COPD-6, Vitalograph, Buckingham, UK) and normalised to percentage of their predicted value (16).

2.6. Physical Activity Measurement

PA was recorded for 7 days at each time point (baseline, 4, 8, 12 weeks), using an accelerometer (GENEActiv; ActivInsights, Kimbolton, UK) worn on the participants non-dominant wrist. Participants were asked to wear it during all waking hours and complete an activity log to

qualitatively describe activity undertaken. Data was analysed in 60-second epochs, using pre-validated cut points (17, 18) and data from at least two days with ten hours each (19) was included for analyses to determine time spent (in minutes, and as percentage of wear time) in sedentary, light, moderate and vigorous PA domains.

2.7. Quality of Life

QoL was assessed using the CF Questionnaire-Revised (CFQ-R) (20), providing an indication of QoL across a range of domains. A value of 100 represents an optimal score.

2.8. Assessment of Feasibility

Feasibility and satisfaction of using video-calling was assessed at 8-weeks using a feedback questionnaire developed in conjunction with the local Research and Development team for the hospital trust (Supplement 1). To determine feasibility, guidelines set by Bowen *et al.* (21) were utilised. Primary areas of evaluation for this particular intervention were demand, implementation (study and session completion), practicality (technical issues) and acceptability (participant feedback). Furthermore, analysis of anthropometric, pulmonary, PA and quality of life (QoL) variables (described below) was purely descriptive in nature, with means and standard deviations reported for each variable, but no formal statistical procedures taking place (due to the feasibility nature of the study and insufficient statistical power).

3. RESULTS

3.1. Demand

Of the nine participants who undertook exercise sessions, two failed to complete the study. Both participants were male (42 years, BMI 27.8 kg·m⁻², FEV₁ 59%_{Predicted} and 26 years, BMI 24.2 kg·m⁻², FEV₁ 23%_{Predicted}) and withdrew due to time constraints, one prior to their first

scheduled exercise session, and one after their first week of the intervention. In contrast, three participants requested to continue delivery of exercise sessions beyond the scheduled study. These participants commenced additional sessions as part of routine clinical care following the one-month follow up observations. No adverse events related to exercise during the study were reported by either participants, nor the exercise therapist delivering the intervention.

3.2. Acceptability of Intervention

Of the participants to undertake exercise sessions, compliance was variable. A total of 88 sessions were booked with participants, with 59 being attended by participants. Individual compliance varied from 3/9 sessions (33%) to 10/10 sessions (100%) (mean = 68%). Of the 29 sessions not attended, reasons included: illness ($n = 13$ [45%]; including 9 missed by one participant's exacerbation leading to admission); work-related commitments ($n = 8$; 28%), school-related commitments ($n = 2$; 7%), unexplained non-attendance ($n = 2$; 7%), transport (to home) issues ($n = 2$; 7%), participant cancellation ($n = 1$; 3%) and vacation ($n = 1$; 3%).

Of the training sessions completed, duration ranged from 12 – 29 minutes (mean = 20 minutes). Sessions fell short of the desired 30 minutes in duration, due to both clinical restraints (e.g. gymnasium bookings, staffing requirements) and participant preferences for shorter sessions. Total contact time between therapist and participants for the 59 attended sessions equalled 18 hours and 21 minutes.

3.3. Implementation

Of the seven participants to complete the post-intervention feedback questionnaire, four had used video-calling software previously: Skype ($n = 2$; 29%); Business Skype ($n = 1$; 14%); iPhone Facetime ($n = 1$; 14%); with three participants (43%) using it for the first time due to

this study. Six of seven participants (86%) reported it was 'easy' to set up Skype, with one (14%) reporting set up as 'OK'.

Participants used differing devices to connect via Skype including laptop ($n = 4$; 57%), smartphone ($n = 2$; 29%) and tablet ($n = 1$; 14%). Connections were made over Wi-Fi ($n = 4$; 57%), broadband ($n = 2$; 29%) and fibre broadband ($n = 1$; 14%), with four participants (57%) reporting connection issues. These issues were experienced on differing devices and types of connection (tablet/Wi-Fi, $n = 1$ [14%]; laptop/broadband, $n = 1$ [14%]; smartphone/Wi-Fi, $n = 1$ [14%]; laptop/fibre broadband, $n = 1$ [14%]). Sound quality was rated 'good' by 3/7 (43%) participants and 'OK' by 4/7 (57%) participants. Video quality was rated 'good' by 4/7 (57%) participants and 'OK' by 3/7 (43%) participants.

A total of 22 technical issues were reported by staff administering the intervention, for 15/59 (25%) sessions. As a proportion of the number of issues, these included connection issues ($n = 8$; 36%); delays/lags ($n = 7$; 32%); as well as visual ($n = 4$; 18%) and sound ($n = 3$; 14%) problems. Technical issues resulted in three video-calls (5% of total) being cancelled.

3.4. Participant Feedback

Participants found using Skype for exercise useful, with ratings ranging from 7/10 – 10/10 (mean = 9/10). Overall satisfaction ratings, with regards to taking part in this research study, included: 'excellent' ($n = 2$; 29%), 'very good' ($n = 3$; 43%) and 'good' ($n = 2$; 29%). All participants (7/7; 100%) stated they would be happy to take part in future research studies.

Four participants provided qualitative feedback via the intervention feedback questionnaire. These comments covered different topics, including their support for, and enjoyment of, the

227 exercise intervention:

228

229 [exercise at home] ...*saved me a lot of hassle, not having to travel up to the hospital for*

230 *exercise* (Participant 1)

231

232 *Really enjoyable & set me up for the day* (Participant 4)

233

234 *I found the Skype session useful* (Participant 7)

235

236 Participants also commented on the use of Skype as the modality of delivering the intervention,

237 with both positive and negative comments:

238

239 *Connection was sometimes poor and a slight delay - was sometimes difficult hearing my*

240 *physio* (Participant 1)

241

242 *Very easy to setup and use. The connection was very good at all times* (Participant 7)

243

244 Comments also highlighted how the disease interfered with the delivery of the intervention:

245

246 *Unfortunately, I was poorly for a couple of weeks so I didn't get to exercise as much as I*

247 *would have liked to* (Participant 1)

248

249 Finally, participants also provided suggestions for further enhancements of the study design,

250 with specific mention of timeline of events:

251

*Would be good to have a tailored timetable at the start detailing when each part is happening
e.g. Week 1: Exercise session x2; Week 2: wear exercise watch; Week 3: Review in hospital
etc. (Participant 9)*

3.5. Participant Outcomes

Participant characteristics are listed in Table 1, with subsequent changes in body size and lung function, PA and QoL included in Tables 1, 2 and 3 respectively. The study was not powered to detect changes in these outcomes and no changes were seen across all variables during the course of the study.

The majority of data was collected at each visit without issue. However, of the seven participants providing follow up data, one did not undertake body composition at 8-weeks, and three SaO₂ measures (one at 8-weeks, 2 at 12-weeks) were missed; all due to non-availability of equipment. Furthermore, for PA data, of the seven participants providing follow up data, seven (of 21; 33%) PA measures across the three time points (4, 8, 12 weeks) were missed. These seven missed measurements were due to one participant not wearing the accelerometer (i.e. non-compliance, $n = 3$; 43%), and the remaining four due to equipment error ($n = 2$; 29%), inpatient admission ($n = 1$; 14%) and loss within the postal service when returning accelerometer to study team ($n = 1$; 14%).

4. DISCUSSION

The purpose of this study was to assess the feasibility and acceptability of using video-calling technology to implement exercise programmes to engage patients with CF in exercise training. Results suggest this modality may be feasible in practice, as it was accepted by participants

and could therefore potentially be used in clinical practice to deliver exercise interventions. Many different aspects of feasibility can be assessed to evaluate new interventions, and this study focused on the demand, implementation, practicality and acceptability (21).

4.1. Demand and Implementation

For assessment of demand and implementation, outcomes of interest include the actual use of the programme and the degree of execution – characterised by the number of participants to complete the study and number of sessions completed.

As with any exercise intervention, a loss of study participants is to be expected, and the withdrawal of two participants (22%) in the present study is comparable to previous training interventions in people with CF, both in terms of percentage of participants (4/18; 22% (22)) and absolute numbers (13). Therefore, given the self-reported reasons of ‘time commitments’ from participants as reasons for withdrawal, and comparable attrition rates to other studies, it can be concluded that use of Skype itself is not a contributory factor in withdrawing from this intervention – a reason for withdrawal that has been previously reported in people with chronic obstructive pulmonary disease (COPD) (23).

In addition to withdrawals, 32% of appointments were missed by remaining participants for various reasons, a lower rate than that seen when using Skype to deliver exercise for chronic knee pain (24). These reasons were related to lifestyle and environmental factors that could feasibly interfere with any intervention (e.g. work commitments) and were not related to the use of Skype or the internet itself. This provides further evidence that the use of a Skype is a feasible platform for use when remotely delivering an exercise intervention.

4.2. Practicality

In order to assess practicality, the ability of participants to carry out the intervention must be considered. Within this study, there were multiple technical issues associated with using Skype, such as connection issues and audio/visual problems. However, these issues were not mutually exclusive and multiple issues could (and did) occur per video-contact session, thus reducing the total number of affected sessions. The 25% of sessions that were affected is a lower rate to that previously reported for an online Yoga intervention for people with COPD and heart failure (25), although the issues are similar (e.g. visual lags).

Individual participants used varying platforms, and connection modalities, to operate Skype and yet all participants reported at least one technical issue. Therefore, no single connection mode or user platform can be associated with technical issues. Furthermore, as only 5% of calls were cancelled as a result of technical issues, this suggests that use of Skype as a delivery modality for exercise sessions is practically feasible. This is supported by previous use of telemedicine in CF in the United Kingdom (UK), whereby connection problems have delayed delivery of the intervention, but do not appear to have negatively affected the acceptability of remote monitoring (26). Given the increased government investment in internet infrastructure in the UK (27), it is likely such technical issues associated with video-calling will reduce in the future, further increasing the feasibility of this intervention modality.

In addition to patients, interventions must also be practically feasible for clinical staff. This current intervention required a total contact time of 18 hours and 21 minutes from the exercise therapist, although this does not include clinical time associated with setting up appointments or preparing programmes for delivery. However, the online nature of sessions does mean that staff can contact patients immediately one after another (as done multiple times in the present

study), reducing the time normally required between meeting patients in the same facility due to cross-infection risks. This can therefore be viewed as an efficient use of clinical time and increases the practical feasibility of using Skype as a modality for exercise delivery.

4.3. Acceptability

Whilst the use of Skype does not appear to be a barrier to participation in an exercise training programme, participant support and enjoyment is fundamentally required for an intervention to be deemed acceptable. Without this participant support, any prospective development of an intervention is unlikely to succeed in the long-term.

Participant feedback was largely positive in this study, with all participants who completed this study being satisfied with the study and reporting Skype as a useful platform. Furthermore, given that three participants requested to continue training sessions via Skype following the intervention, this suggests acceptability of this modality. Qualitative comments were mixed; although negative comments were related to technical issues associated with connection (which could be overcome with advancements/upgrades in software/internet speeds), as opposed to the use of an online platform and the burden of the disease itself. Positive responses to the intervention are in agreement with previous studies to utilise Skype in CF (28), osteoarthritis (29) and breast cancer (30).

4.4. Anthropometrics, Pulmonary Function, PA and QoL

As this study was not powered or designed to identify changes in function over time, analysis of data is limited to descriptive statistics only. However, the majority of measures were collected without issue, with the technical issues and loss within the postal system having been experienced by other studies previously (31). Furthermore, the purpose of the study was to

remotely *supervise* exercise, not to remotely *monitor* exercise responses and as such, the loss of data impacts only upon our understanding of habitual PA and does not impact upon clinical decisions that may be made on account of monitoring, as incorporated into other prospective monitoring interventions (32).

When examining the data obtained from the study, mean values for all anthropometric, pulmonary, PA and QoL factors appear to have remained stable, suggesting maintenance of function when engaging in an online exercise regimen over a 12-week period. The wide standard deviation associated with each variable is likely due to a) the range of disease severity within the recruited group (as shown by baseline FEV₁ ranging from 23 – 121% predicted [data not reported]), and b) admissions to hospital due to pulmonary exacerbations experienced by participants. Regardless, the lack of an overall decline in function aligns with previous studies in other clinical groups that have utilised Skype to remotely deliver exercise interventions, such as COPD (23), breast cancer (30) and chronic knee pain (24), all of which have found positive outcomes associated with online-delivered exercise.

As patients with CF are recommended to undertake PA as part of disease management (3), the challenge for clinical staff is how to implement this on a personalised level, and ensure compliance. Whilst the mean duration of exercise sessions in this study was 20 minutes, below the 30 minutes of recommended daily PA (3), it has been shown that accumulation of bouts of as little as 10 minutes of MVPA could yield long-term benefits in CF (33). Therefore, use of telehealth could prove to be an integral component of future care and possibly reduce the time required on behalf of clinical teams to engage patients in exercise and PA.

The findings of the present study have implications for clinical practice, by identifying issues associated with a platform that has the potential to overcome geographical barriers and reduce cross-infection risks.

4.5. Study Limitations

The small samples size (due to the feasibility driven approach of this investigation) will limit the utility of findings to further groups of individuals with CF, although the findings can be used to statistically power future studies. Furthermore, the variances in the types of exercise undertaken by each participant has the potential to bias results. Whilst a uniform training regimen would alleviate such bias, it would remove the personalised approach to each training regimen that can improve acceptance and adherence. This therefore, provides a challenge for future researchers to accommodate this trade-off between uniform and personalised approaches to exercise prescription.

In conclusion, this feasibility study demonstrated that use of Skype as a telehealth platform can be successfully used to engage patients with CF in a personalised exercise regimen, and that the participants in this study responded positively to this approach. Future research is warranted to identify whether the utility of this delivery modality can effectively improve health and physical function in CF.

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Table 1. Changes in anthropometric and pulmonary variables over the course of the study period.

	Baseline (0 weeks)	Intervention End (8 weeks)	Follow Up (12 weeks)
	<i>n</i> = 7	<i>n</i> = 7	<i>n</i> = 7
Age (years)	30.0 (8.6)	30.2 (8.6)	30.3 (8.6)
Height (m)	1.64 (0.09)	1.64 (0.09)	1.64 (0.09)
Weight (kg)	61.9 (14.8)	62.2 (14.2)	62.8 (14.7)
BMI (kg·m ⁻²)	22.8 (3.7)	23.0 (3.6)	23.1 (3.6)
Fat Mass (kg)	13.2 (6.3)	14.0 (6.5)	13.4 (6.7)
Fat Mass (%)	20.8 (9.2)	21.1 (8.0)	21.1 (9.7)
Fat Free Mass (kg)	48.7 (11.4)	50.8 (11.0)	49.4 (12.5)
Fat Free Mass (%)	79.2 (9.2)	78.9 (8.0)	78.9 (9.7)
Resting SaO ₂ (%)	97 (1)	97 (2)	98 (1)
FEV ₁ (L)	2.53 (1.47)	2.51 (1.55)	2.54 (1.43)
FEV ₁ (% _{Predicted})	74 (31)	73 (34)	73 (32)
FVC (L) ^a	3.65 (1.68)	3.61 (1.71)	3.58 (1.49)
FVC (% _{Predicted}) ^a	93 (25)	91 (27)	90 (22)
Homozygous ΔF508		3	
Heterozygous ΔF508		4	
Other Alleles	E1371X, Q220X, 2789+5G>A, D1152H		

All values reported as mean (SD). BMI, body mass index; FEV₁, forced expiratory volume in 1 second; FVC, forced vital capacity. Data presented for *n* = 7 to demonstrate the seven participants who completed the study. a: FVC only available for 6/7 participants due to positive screen of non-tuberculosis mycobacterium in one participant, whereby subsequent use of personal spirometer only provides FEV₆, not FVC.

Table 2. Changes in physical activity over the course of the study period.

	Baseline (0 weeks)	Mid-Intervention (4 weeks)	Intervention End (8 weeks)	Follow Up (12 weeks)
Activity Domain	<i>n</i> = 6 ^a	<i>n</i> = 4 ^b	<i>n</i> = 6 ^c	<i>n</i> = 4 ^d
Sedentary (mins·day ⁻¹)	528 (86)	565 (61)	470 (66)	513 (151)
Sedentary (%)	65 (8)	67 (13)	65 (12)	63 (20)
Light (mins·day ⁻¹)	96 (20)	85 (6)	86 (40)	98 (33)
Light (%)	12 (3)	10 (1)	14 (9)	13 (4)
Moderate (mins·day ⁻¹)	180 (72)	201 (129)	193 (104)	196 (148)
Moderate (%)	22 (7)	23 (13)	24 (10)	24 (16)
Vigorous (mins·day ⁻¹)	5 (5)	6 (8)	4 (4)	2 (3)
Vigorous (%)	1 (1)	1 (1)	1 (1)	0 (0)

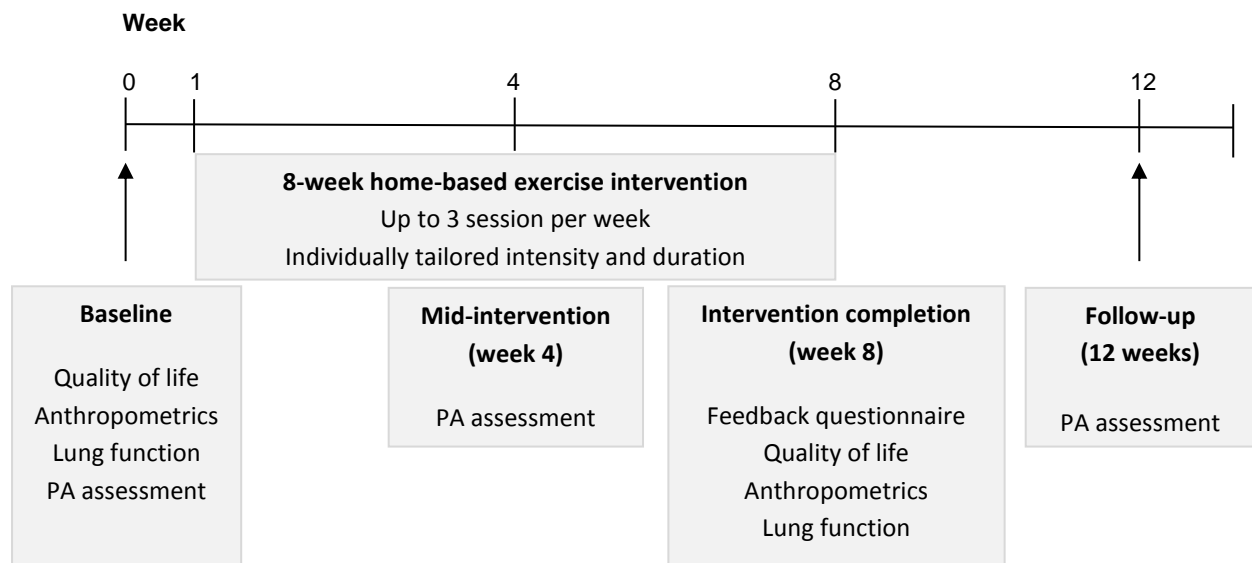
All values are presented as means (SD). a: Baseline values for six participants, accounting for all individuals to complete study (*n* = 7), and loss of data due to non-wear of accelerometer (*n* = 1). b: 4-weeks only includes four participants due to withdrawal (*n* = 2), non-wear of accelerometer (*n* = 1), inpatient admission unrelated to interventions (*n* = 1), and loss of accelerometer within postal system (*n* = 1). c: 8-weeks only includes six participants due to withdrawal (*n* = 2) and non-wear of accelerometer (*n* = 1). d: 12-weeks only includes four participants due to withdrawal (*n* = 2), equipment error (*n* = 2), and non-wear of accelerometer (*n* = 1).

Table 3. Changes in quality of life (QoL) over the course of the study period.

	Baseline (0 weeks)	Intervention End (8 weeks)	Follow Up (12 weeks)
QoL Dimension	<i>n</i> = 6 ^a	<i>n</i> = 6 ^b	<i>n</i> = 7 ^c
Physical	72 (34)	58 (37)	72 (33)
Vitality	56 (25)	51 (21)	56 (24)
Emotion	71 (27)	71 (18)	79 (18)
Eating	80 (25)	83 (18)	88 (17)
Treatment Burden	56 (36)	37 (24)	49 (33)
Health Perception	70 (24)	37 (38)	52 (34)
Social	74 (16)	62 (19)	62 (29)
Body Image	69 (29)	69 (28)	73 (27)
Role	75 (27)	65 (38)	77 (28)
Weight	67 (42)	67 (30)	71 (36)
Respiratory	52 (33)	56 (23)	64 (27)
Digestive	85 (22)	91 (11)	87 (20)

All values are presented as means (SD). a: Baseline values for six participants, accounting for all individuals to complete study (*n* = 7), but failure of one participant to complete baseline QoL (*n* = 1). b: 8-weeks only includes six participants due to withdrawal from study (*n* = 2) and loss of QoL questionnaire within postal system (*n* = 1). c: 12-weeks only includes seven participants due to withdrawal from study (*n* = 2).

Figure 1. Schematic representation of assessment and intervention time points.



SUPPLEMENTARY FILES

Supplement 1. Study feedback questionnaire administered to participants, following 8-week intervention.

SKYPE STUDY FEEDBACK QUESTIONNAIRE.

Thank you for taking part in this Research Study at the RD&E. We would be grateful if you would complete this questionnaire about your experience as a Research participant so that we can improve the service we provide.

The information you provide will be collected by the Research and Development team and will be treated in the strictest confidence. It will not affect any further treatment or participation in a Research Study.

Thank you.

<u>About Skype.</u>										
Did you use Skype or similar software before now?								<input type="checkbox"/> YES	<input type="checkbox"/> NO	
If YES please state which software you used:										
How easy/difficult was it to set up Skype?								<input type="checkbox"/> EASY	<input type="checkbox"/> OK	<input type="checkbox"/> DIFFICULT
Which (if any) issues did you encounter?										
What device are you using for Skype?				<input type="checkbox"/> DESKTOP	<input type="checkbox"/> LAPTOP	<input type="checkbox"/> TABLET	<input type="checkbox"/> SMARTPHONE			
Have you had any connection issues?								<input type="checkbox"/> YES	<input type="checkbox"/> NO	
What internet connection are you using?		<input type="checkbox"/> 3G	<input type="checkbox"/> 4G	<input type="checkbox"/> BROADBAND	<input type="checkbox"/> FIBREBROADBAND		<input type="checkbox"/> WIFI			
How was the sound quality?				<input type="checkbox"/> GOOD		<input type="checkbox"/> OK		<input type="checkbox"/> BAD		
How was the video quality?				<input type="checkbox"/> GOOD		<input type="checkbox"/> OK		<input type="checkbox"/> BAD		
Did you find using Skype for an exercise session useful?										
Not at all 1 2 3 4 5 6 7 8 9 10 very useful										
How could this format of appointment be improved?										
Overall comments/opinions:										

<u>About the Study.</u>		YES	PARTLY	NO					
Was the study information sheet easy to understand?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Did the Research Team answer questions about the study in a way that you could understand?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Did you know what was expected of you when you agreed to take part in the study?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Do you feel it is important to take part in Research?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					
Would you be happy to take part in another Research Study?		<input type="checkbox"/>		<input type="checkbox"/>					
<u>General Satisfaction.</u>									
	POOR	FAIR	GOOD	VERY GOOD	EXCELLENT				
My overall satisfaction with taking part in this Research Study is:-	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
<u>Please add any further comments about your experience of taking part in this study:-</u> <hr/> <hr/>									
<u>Please tell us your reasons for taking part in this study. Circle all the options which apply.</u>									
1) To help others	2) Own benefit	3) Felt obliged	4) Other – please specify: _____						
ADDITIONAL INFORMATION – PLEASE CIRCLE									
AGE GROUP	11-16	17-21	22-30	31-40	41-50	51-60	61-70	71-80	80+
Thank you for your help.									
RESEARCH TRIAL INFORMATION TO BE COMPLETED BY STUDY TEAM									
Study Title:					R&D Number:				